

Angry?  
Confused?  
Overwhelmed?

**SURVIVAL AND HOPE FOR FAMILIES AFTER THEIR  
CHILD'S INITIAL DIAGNOSIS WITH A CHRONIC HEALTH CONDITION OR DISABILITY**



You have recently been told that your child has serious medical problems. There is no right way to feel or react when you get news like this.

*“When we heard this news my husband and I were devastated.”*

*“Why us? What did we do to deserve this?”*

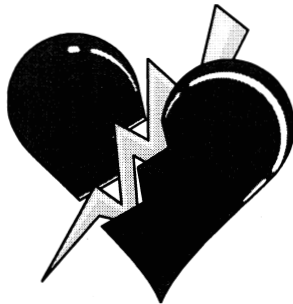
*“The day we found out about our son’s impairment was, to say the least, a day of feeling like we had been hit by a Mack truck.”*

Anger, confusion, and a sense of being overwhelmed are just a few of the many feelings you may experience when you learn that your child has a chronic health condition or a disability.

One of the most intense feelings families may experience is that of **anger**. You might feel angry at God for allowing this to happen, angry at yourself or your spouse, angry at the doctor for giving you this news, or even angry at your child for causing this disruption to your family.

*" I remember thinking life isn't fair. We were brought up to think if we do good, life will repay us. So therefore, if something like this happens, I must have done something wrong. And that made me angry."*

*" ....knowing you did everything right along the way and being angry for the pain God was putting you and your child through..."*



Families also talk about feeling **confused**. There is so much information to try to understand and also many questions without answers. You may also feel frustration and fear about the future.

*"My major feeling was fear. Fear for my child and her future... Fear that I couldn't handle this - and I didn't even know what it was I was having to handle."*

Some parents may feel **overwhelmed**, helpless and even exhausted by the demands of the circumstances that must now be dealt with. Others describe themselves as begin paralyzed and incapable of making decisions.

*"We weren't sure what to expect. We were first time parents and overwhelmed by all that was happening to us."*



Shock is a normal reaction to trauma. It prevents your mind and body from being overwhelmed.

*" ... listening to doctors and nurses and having no clue what we were in for... feeling like a robot in a world of fog..."*

**Stress**, including fatigue and other physical symptoms, is also normal because you are using all of your energy to deal with your emotional reactions to the situation.

*"... I had no appetite and could not sleep... even tears came less often..."*

You may feel **resentment** and envy toward others with typical children.

*" ... having a hard time watching children on the playground..."*

You may **grieve** for the hopes and dreams for your child's future that may now have changed. You might feel **guilty** as you try to understand what went wrong and look for an explanation.

*"Reliving each day to that point looking for reasons... blaming myself and not knowing for what..."*

All of these feelings are normal. Just as there is no right way to feel, there are also no set stages or time tables that you should go through as you cope and react to these circumstances.

However, experienced parents have talked about two stages that they went through when their child was first diagnosed with a chronic health condition or disability. They could be labeled Surviving and Searching. The Searching stage involves the search for answers, and eventually searching for the services and programs needed by their child.

The first stage is aptly named **Surviving** because at first parents not only worry about whether their new baby will survive but also whether they will survive their initial shock and disappointment.

*"Surviving is what you do to keep going when you are feeling completely helpless because something totally out of your control has taken away your child's equal chance at life. Being in a state of survival doesn't last forever. It just seems that way at the time."*

Other families who have had a child with a health problem or disability said they dealt with their circumstances, and thus survived, in two ways; by COPING and REACTING. COPING is *"doing what you have to do one problem at a time - getting by"*.

*"... waking up each day and praying there would be better news... accepting each day one at a time."*

There are many ways of REACTING, but two of the most helpful reactions are to make sure you make time for yourself make sure you seek out and use support networks.

Make time for yourself by making time to:

- \* Be alone - to grieve, to heal, to think, and to rest your mind.
- \* Be with your partner to nurture your couple relationship.
- \* Be with your other children and keep their lives in balance.
- \* Be with friends who understand and support you.
- \* Exercise, to have fun, and to keep your own sense of balance.

*" ... you realize that in order to go day to day you need to get involved..."*



## Use support networks

It's often tempting to shut other people out of your life and feel you have to carry your responsibility alone, but try not to reject the people who are reaching out around you. Others want to be there for you, but you may need to tell them what to do and how to help. Family, friends, health care professionals, parent-to-parent programs and parent support groups are sources of support, reassurance and hope for the future.

*"It really helps to see other families and see that they got through. You see that they all have the same problems - or even worse ones - and they're still laughing and smiling, and taking vacations. It gets you 'up' again."*

*"I talk to other parents. There's no substitute for that. You find out you're not alone. You're not the only one with those concerns."*



**Searching** Rather than being separate stages, Surviving and Searching actually go hand in hand. Searching begins when you are still struggling with the issues of Survival. Taking care of your child and finding help for your child cannot wait until you have resolved all of the feelings and questions you are dealing with. Families are both Surviving and Searching at the same time.

*"We were tired of feeling victimized, so we decided to do something that would help us feel more powerful... we began to feel we could gain some control over our lives."*

Other families of children with health problems or disabilities talk about two kinds of searching. One is outer searching in which you search for answers to your child's problems. Parents ask "What's wrong with my child and can it be fixed? The other kind is inner searching in which you try to understand what those problems will mean in your life.

There is no best order in which you should search and one kind of searching is no more or less important than the other. Some of the things other parents said they began searching for include:

The search for an **EXPLANATION**, a reason, and sometimes, even a cure. Parents who may feel guilty can be reassured because during this search, you usually find out that there was nothing you did to cause the problem.

*"What I was looking for was someone who would tell me what I wanted to hear - that it would go away."*

The search for a **DIAGNOSIS** or a label for your child's problem - to help you know what you're dealing with. Once you have a diagnosis, be careful not to let stereotypes limit your expectations of what your child will or will not be able to do.



The search for **INFORMATION** about your child's diagnosis, needs, and the programs and services available to meet those needs. The knowledge gained from this search for information can help restore a sense of power and control.

*"The problems don't go away, they just change. But after a while you realize you can get through them."*

The search for **SUPPORT** and **UNDERSTANDING**. In this search, you can begin to identify friends and professionals that you can trust to provide support, understanding and factual information.

*"You work at finding answers to questions that parents of typical children may never have to spend much time on."*

The search for **PERSONAL GROWTH** and **DEVELOPMENT**. The process of self-improvement can help improve your competence and self-confidence and helps to balance your child's needs with your own needs and those of your spouse and other children.

*" I have capabilities I didn't know I had."*



## Hope for the Future

Acceptance can be thought of in one of two ways. Accepting your situation by sitting back and not seeking or expecting help or improvement for your child takes away all of your control and confidence.

A second kind of acceptance means you acknowledge your child has special needs, take it in, put up with the disability, and make the best of it.

*"OK, I get it. The problem is here and it's not going away. How do we understand it, integrate it into our lives, and make it the best it can be for our child and our family?"*



This kind of acceptance can help give families hope for the future.

As time passes, the intense feelings you experienced earlier will come back at times, but they will not come back as often and will not be as intense. You will have a greater sense of control over them.

*"We're all doing better than we used to. The difficult times are shorter. It used to last a week and now it's just moments."*

As you integrate your child's special needs into your family life, normal routines and stability will begin to return. You will also begin to focus more on what your child can and will be able to do instead of what they cannot do.

*"I'm going to let her be just who she is."*

Right now the future may seem frightening and uncertain. But you will survive and, in your own time and in your own way, be able to react, cope, search, accept, and look to the future with confidence and hope for your child.

*"This is my kid, and I don't care what is wrong with her. I love her for who she is"*



This booklet was developed by the Family Advisory Council to the Children's Special Health Services Division in the North Dakota Department of Human Services. Many of the quotes in this publication were taken directly from Family Advisory members or other North Dakota families who have children with chronic health conditions or disabilities.

This publication is the result of Family Advisory Council members' desire to share their knowledge and experience with other families that have children with special health care needs. We hope that ***Angry? Confused? Overwhelmed?*** effectively speaks to families initial concerns for their child with special needs and provides hope for your child's and family's future.

Families are also encouraged to read ***Speaking Up For Your Child; Advocating In the Health Care System For Your Child With Special Needs***. This booklet is published by Pathfinder Resources, Inc. of Minnesota and can be obtained by calling Children's Special Health Services toll-free in North Dakota at 1-800-755-2714.

## **North Dakota Resources**

### **Children's Special Health Services (701) 328-2436 or 1-800-755-2714**

Information and services for children with special health care needs and their families.

### **The Arc (701) 223-5349**

Information, support, and advocacy for families of children with developmental disabilities.

### **Disability Services Division (701) 328-8930 or 1-800-755-8529**

Information about early intervention services, family support services, and Developmental Disabilities case management services.

### **North Dakota Family Voices (701) 493-2333 or (701) 583-2591**

A statewide grassroots network of families and friends speaking on behalf of children with special health care needs.

### **Pathfinder Family Center (701) 852-9426**

Educational related information resources, information, and support.

### **ND Family to Family Network 1-888-434-7436 or (701) 777-2359**

A statewide program in which parents can be matched with experienced or "veteran" parents for support and information.

### **Social Security Administration 1-800-772-1213**

Information about eligibility and application procedures for Supplemental Security Income (SSI) benefits.